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Province	Researchers	Trainees	Lived experience	Advocates	NH staff, managers	Health system, Gvt.	Staff
Ontario	Matthias Hoben NPA, YorkU	Hom Shrestha PhD student	Ron Beleno Caregiver	Cathy Barrick ASON		Kelly Kay PGLO	Gabriel Dusing Data analyst
	Amit Arya KU-Co-A, McMasters	Suad Azar Prosp. PhD student	Shelley Resaul-Nowrattan Older adult, caregiver	Samantha Peck Family Councils ON		Maria Singh MHLTC	Stella Medvedyuk Research coordinator
			Anne Vatistas Older adult, caregiver				
New Brunswick	Pam Jarrett KU-PA, Dalhousie			Chandra MacBean ASNB			
Nova Scotia	Janice Keefe Co-I, MSVU			Sacha Nadeau ASNS		Vicki Elliott-Lopez NS Health & Wellness	
	Katie Aubrecht Co-I, StFX			Michele Lowe NSHA		Susan Stevens NS Health	
Manitoba	Malcolm Doupe Co-I, UMB			Erin Crawford ASMB		Vikas Sethi Shared Health	Jennifer Pietracci Research Prog. Mgr.
	Christine Kelli Co-I, UMB					Gina Trinidad WRHA	
						Barbara Wasilewski MB Health	
Alberta	Carole Estabrooks PA, UofA	Rashmi Devkota PhD student	Patricia Kostyk Caregiver	George Andrews ASANT	5 staff members Zetter, Good Sam	Suzanne Maisey Alberta Health	Emily Dymchuk Study coordinator
	Steph Chamberlain Co-A, UofA	Shovana Shrestha PhD student	Bernie McCracken Older adult, caregiver		5 staff members Sherwood Care	Eleanor Risling AHS	
	Hannah O'Rourke Co-A, UofA						
	Jordana Salma Co-A, UofA						
British Columbia	Kelli Stajduhar PA, UBC		Jim Mann PlwD	Jennifer Perry ASBC	Karen Littleton Interior Health	Karen Neilson MoH	Kyle Corbett Study coordinator
			Katrina Prescott Caregiver	Barb McLean FCBC	Jessica Howard Interior Health	Suzanne Fox Fraser Health	
			Linda Woo Caregiver				
National and International	Sube Banerjee Co-A, UNottingham		Kevin Lazaruk Caregiver	Laura Tamblyn Watts Pres./CEO CanAge			
	Anna Beeber Co-A, Johns Hopkins			Anne Boyle CSPCP			



To the funders, all team members who are supporting this work, and to the persons living with dementia, their caregivers, and care settings who have participated in the various parts of this research



Thoughts about LTC home residents' QoL from the perspective of Hom and Sam

What does QoL mean?

“It is sadly narrow to define quality as the absence of negative outcomes. Absence of bedsores, absence of depression, absence of malnutrition—these are hardly evidence of a good quality of life or goals to inspire generations of care providers.”

Rosalie A. Kane, Gerontologist 41(3), p. 297

RAI-MDS 2.0



Quality of care

Objective indicators of unfavorable outcomes

Not routinely measured



Quality of life

A person's physical, emotional and social well-being



Multiple other factors

E.g., relationships, sense of purpose, social determinants



Reduced ability to verbally communicate



Quality of the moment versus quality of life



Availability of family/friends



Accuracy of proxy reports



Questionnaire actually measuring QoL



Resource constraints

Challenges in measuring QoL



Criteria an ideal QoL measure should meet

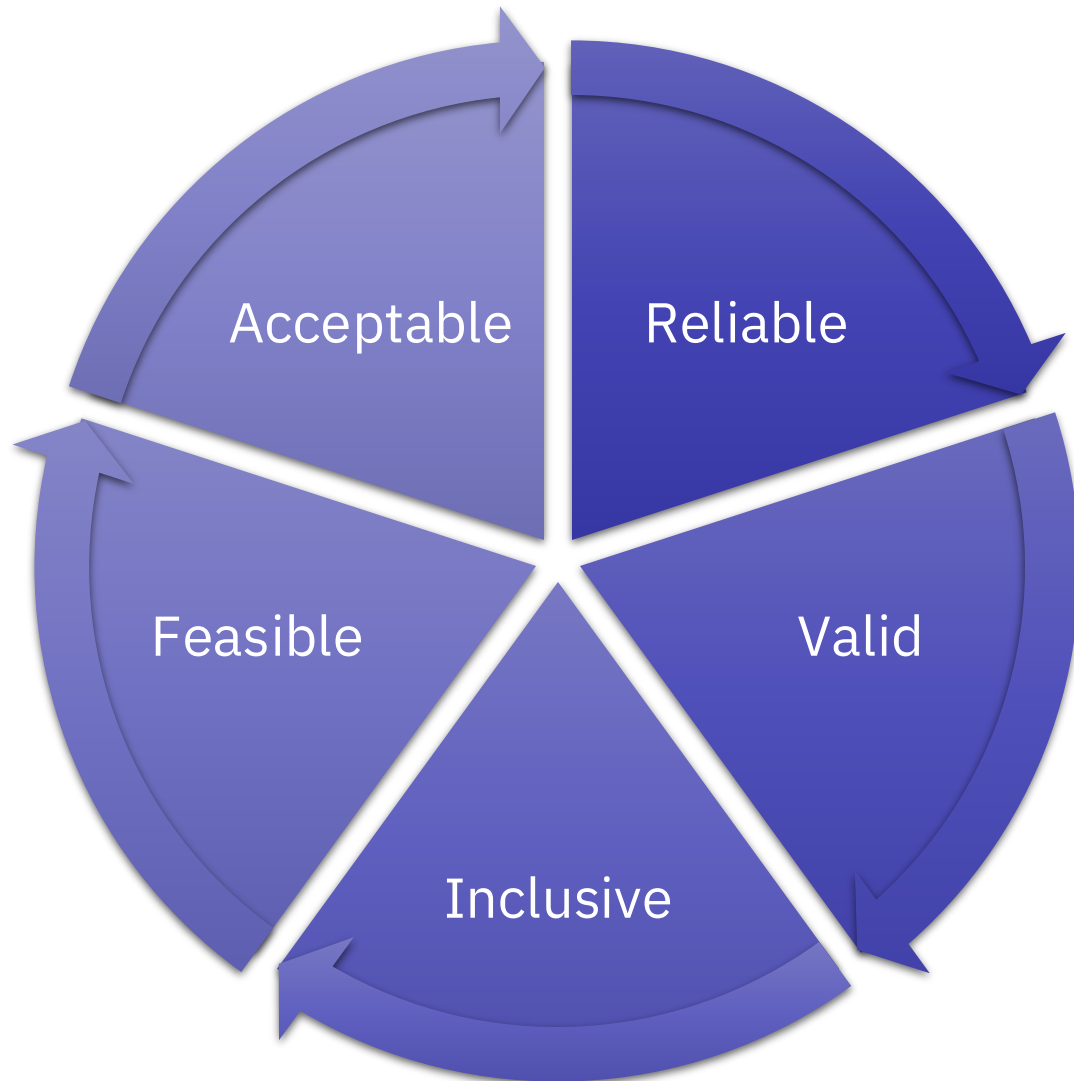


Table 1

Overview of tools available to assess QoL or i-QoL in people with dementia

Acronym	Full name
--	Activity and Action Rating scales
ACSA	Academic Compensatory Self-Assessment Scale
ADROL	Activities Disease Related Quality of Life
SASQoL	Self-Assessment of Subjective Quality of Life in Dementia
--	Physician i-QoL index
CBS	Cornell Error Scale
CDQ-P	Community Dementia Quality of Life Profile
COOP/WONCA	Cooperative Functional Assessment Charts/World Organization of National Colleges, Academies and Academic Associations of General Practitioners/Family Physicians
DCM	Dementia Care Mapping
DEMQUAL	
IQoL	i-Dementia Quality of Life
EQ-5D-5L	--
HL-CE	Health-Related Quality of Life in Dementia
HLI	Health-Related Index Scale 1
MCQ	Mild Cognitive Impairment Questionnaire
QoL-AD	Observing Quality of Life in Dementia (also a version for advanced DL dementia available)
FGS	Frailty Deterioration Scale
FES-AD	Frailty Events Schedule
FGC-FRS	Frailty in Geriatric Center Action Rating Scale
FGC-MC	Frailty in Geriatric Center Moral Scale
--	Frailty Quality of Life Domain Measure
PWS-QP	Psychological Well-Being in Cognitively Impaired Persons
QAA-P	Quality of Life in Alzheimer's Disease—Partner
QoL-AD	Quality of Life in Alzheimer's Disease
QoL-D	Quality of Life in Dementia
QOLAS	Quality of Life Assessment Schedule
--	Quality of Life Face Scale
QoL	Quality of Life Scales
QoL-D	Quality of Life in Late-stage Dementia
QoL-DEM	Quality of Life instrument for proxy completion
RDOC-QoL	Resident and Staff Observation Checklist of Quality of Life
HLI-2015-16	--

We examined over 30 tools that have been used to assess the QoL of PwD in NHs

BMJ Open Psychometric properties and use of the DEMQOL suite of instruments in research: a systematic review protocol

Matthias Hoben ¹, Stephanie A Chamberlain, ² Hannah M O'Rourke, ¹ Brittany Elliott, ³ Shovana Shrestha, ⁴ Rashmi Devkota, ⁵ Trina Thorne, ⁶ Jenny Lam, ⁷ Sube Banerjee, ⁸ Laura Hughes ⁹, ¹ Carole A Estabrooks ¹

Development & validation of the DEMQOL

Extensive review of the literature and consultation with PwD, caregivers, care staff => **conceptual framework**

Development and validation of the DEMQOL & DEMQOL-Proxy

Extensive validation and use of these two tools

Development and validation of the DEMQOL-CH

Our Canadian feasibility and validation work

Measurement of health-related quality of life for people with dementia: development of a new instrument (DEMQOL) and an evaluation of current methodology

Smith S, Lamping D, Banerjee S, Harwood R, Foley B, et al.

Funding:

J Health Technology Assessment Volume: 9, Issue: 10, Published in March 2005

Aging & Mental Health, 2015
Vol. 19, No. 1, 13–31, <http://dx.doi.org/10.1080/13607863.2014.915923>



BMJ Open Adaptation of the DEMQOL-Proxy for routine use in care homes: a cross-sectional study of the reliability and validity of DEMQOL-CH

Laura J Hughes,^{1,2} Nicolas Farina,¹ Thomas E Page,² Najj Tabet,¹ Sube Banerjee¹



Research Article

What constitutes health-related quality of life in dementia? Development of a conceptual framework for people with dementia and their carers

Sarah C. Smith, Joanna Murray, Sube Banerjee, Beth Foley, Joanna C. Cook, Donna L. Lamping, Martin Prince, Rowan H. Harwood, Enid Levin, Anthony Mann

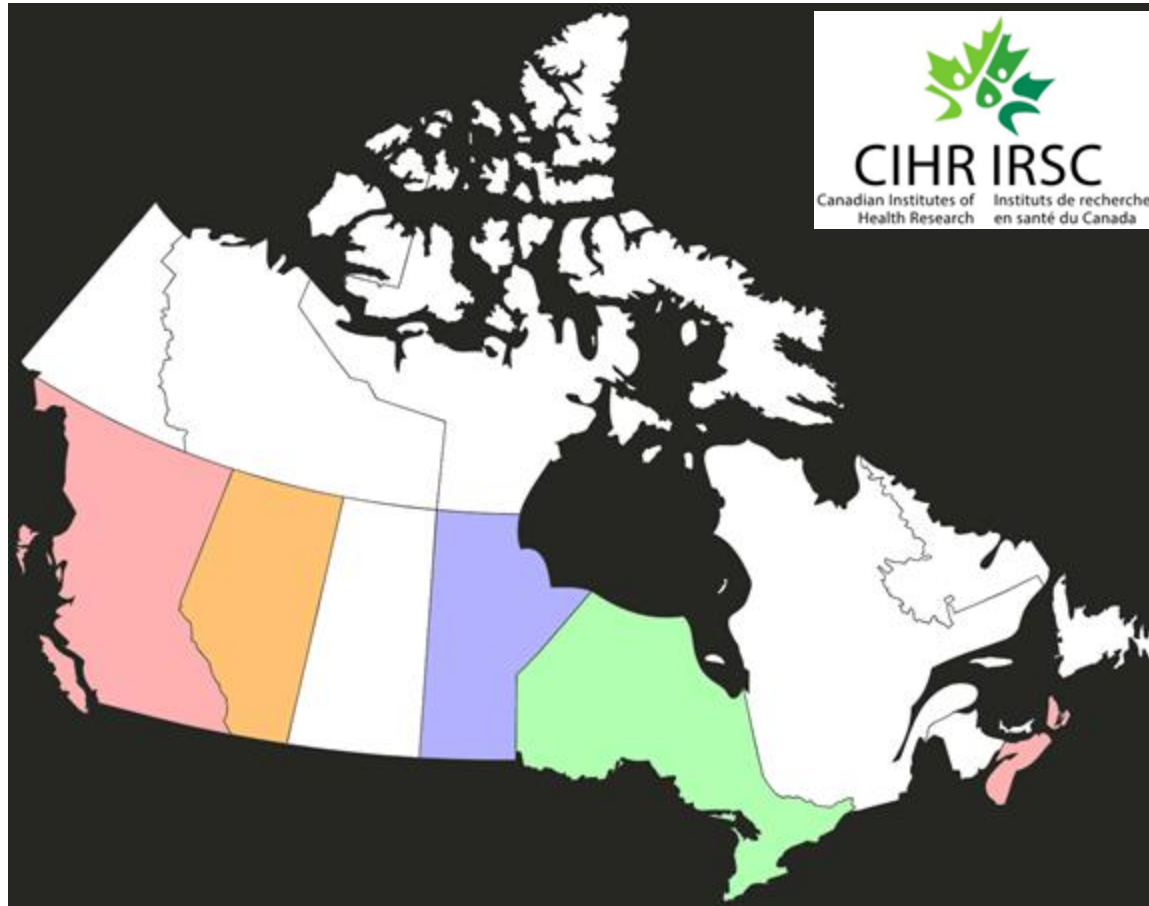
First published: 22 August 2005 | <https://doi.org/10.1002/gps.1374> | Citations: 77

Psychological Medicine, 2007, 37, 717–746. © 2006 Cambridge University Press
doi:10.1017/S0033291706009489 First published online 19 December 2006 Printed in the United Kingdom

Development of a new measure of health-related quality of life for people with dementia: DEMQOL

S. C. SMITH^{1,2}, D. L. LAMPING¹, S. BANERJEE^{1*}, R. H. HARWOOD¹, B. FOLEY¹, P. SMITH¹, J. C. COOK¹, J. MURRAY¹, M. PRINCE¹, E. LEVIN¹, A. MANN¹ AND M. KNAPP¹

The Counting What Counts Study



10% sample (stratified random) of LTC homes

Five Canadian provinces (BC, AB, MB, ON, NS)

Assess QoL of those living in NHs and SDH not routinely collected

Link to the routinely collected RAI-MDS data

The Counting What Counts sample

Province	Nursing homes	Residents	N (%) RAI available	Staff
Alberta	15	667	624 (93.6%)	128
British Columbia	21	941	745 (79.2%)	121
Manitoba	8	460	460 (100%)	55
Ontario	21	994	950 (95.6%)	27
Nova Scotia	5	171	171 (100%)	132
Total	70	3,233	2,950 (91.2%)	463



Women



85+ years



Education
< high school



Immigrants



Other than
White



English as
additional
language



Indigenous



Non-Christian
religion



32.9%

Large (< 120 beds)



20.0%

Rural



31.4%

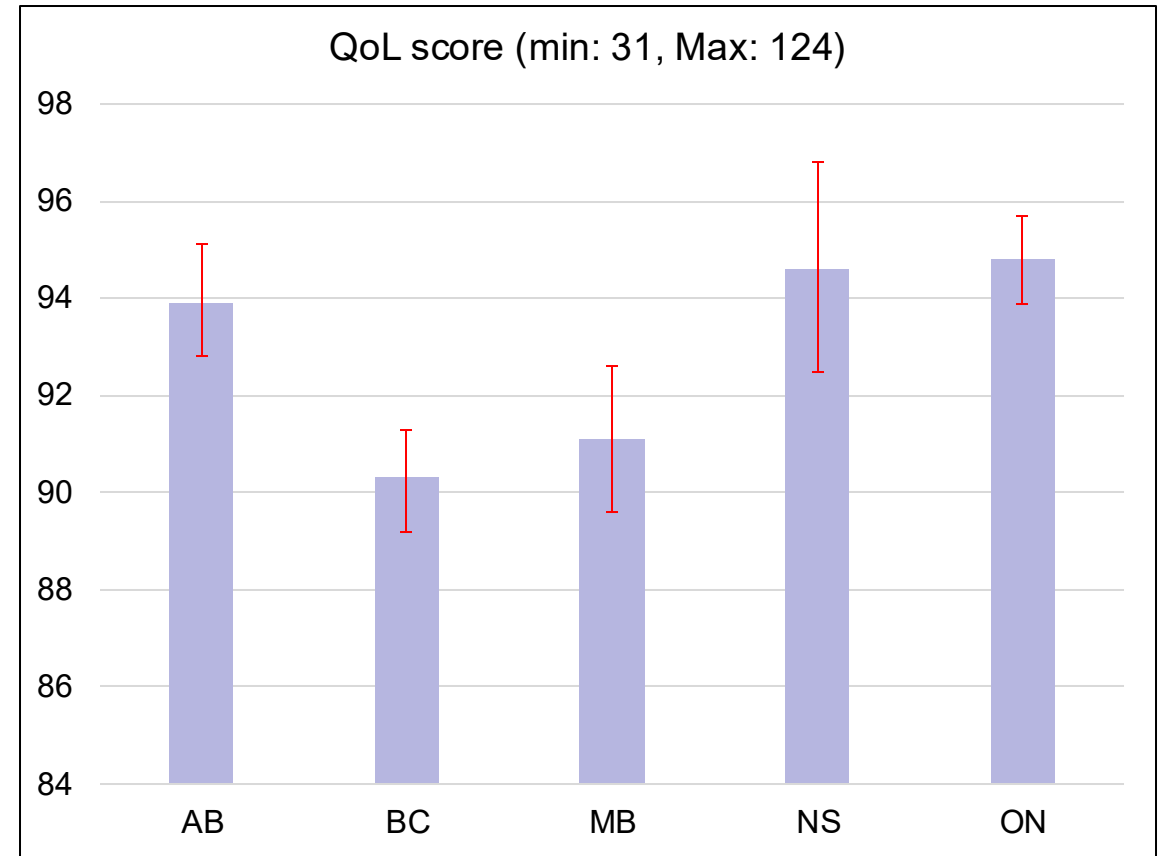
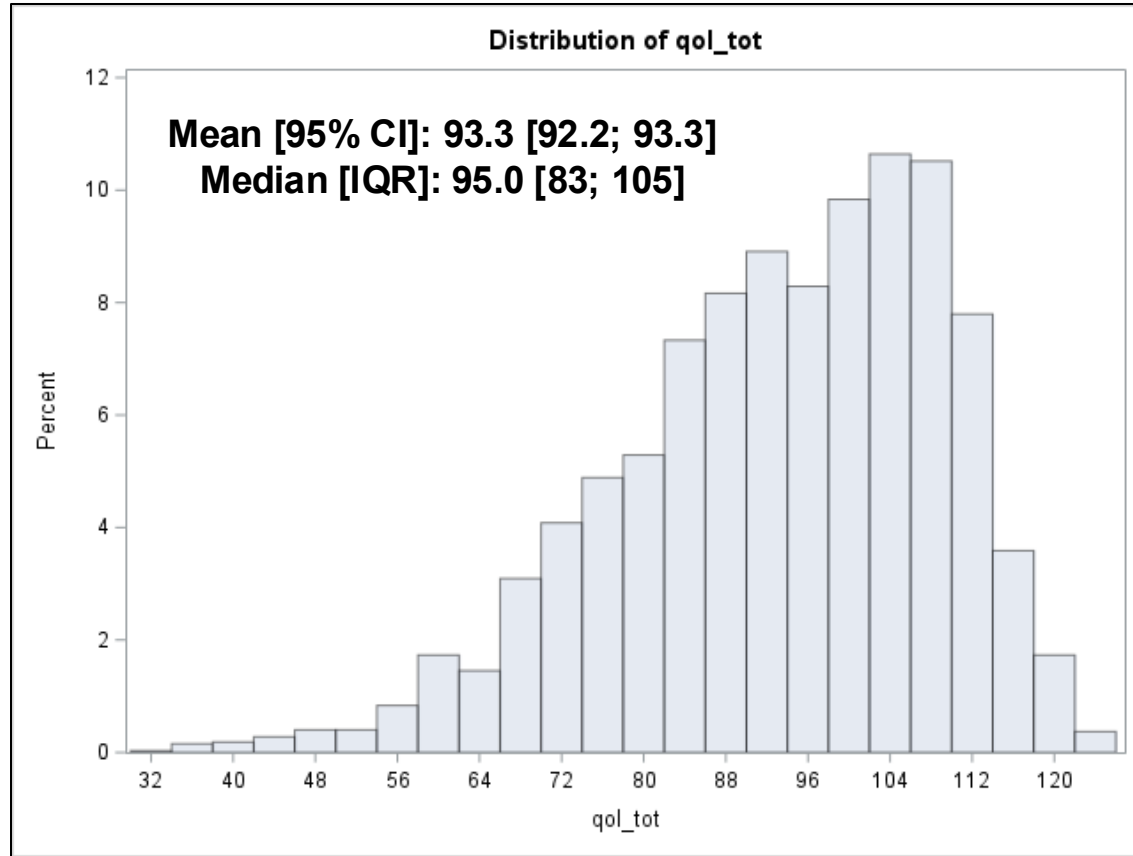
For-profit



34.3%

No person-centred
care model

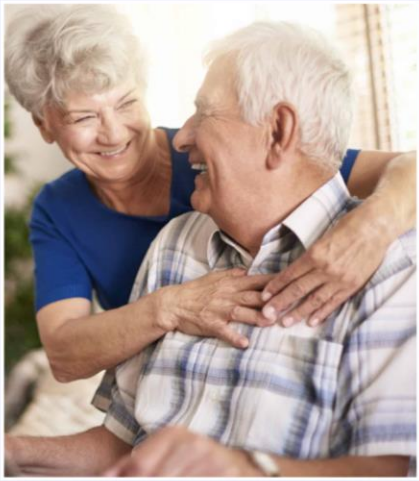
QoL distribution overall and by province



Women < Men
Racialized > non-racialized
Rural > urban
Large home < small Home

Next steps: statistical models assessing social determinants of QoL, profiles of residents with high/low QoL

Feeding back and discussing data with interest holders

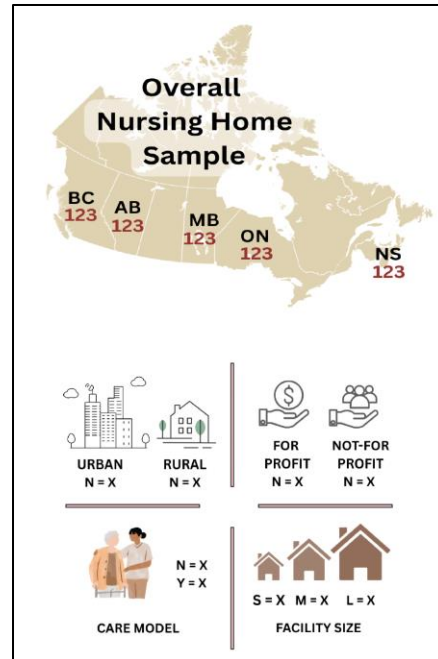


Quality of Life Feedback Report
for Facility 50

Société Alzheimer Society CANADA

YORK UNIVERSITY

Facility-specific
and region-
specific feedback
reports



Summary graphics,
lay explanations

(comparing home
to other homes
in region/province)

Item Label	Average of Score
Cheerful	2.72
Worried/Anxious	2.55
Frustrated	2.67
Full of Energy	2.61
Sad	2.58
Content	2.58
Distressed	2.69
Lively	2.72
Irritable	2.61
Fed Up	2.52
Things to Look Forward to	2.49
Memory in General	2.57
Long-Term Memory	2.51
Short-Term Memory	2.67
Remembering Names	2.67
Remembering Place	2.67
Remembering Day	2.66
Thoughts Muddled	2.67
Difficulties Making Decisions	2.55
Making Self Understood	2.49
Washing/Bathing	2.46
Look Nice	2.66
Getting Things from Shops	2.60
Paying for Things	2.57
Finances	2.57
Things Taking Longer	2.48
Getting in Touch With People	2.52
Enough Company	2.67
Helping Others	2.57
Feeling Useful	2.61
Physical Health	2.70

QoL breakdown
by item

QoL Items	Item-level DEMQOL-CH Scores									
	20	98	163	170	194	273	306	413	474	490
Cheerful	3	3	3	2	2	2	2	4	2	2
Content	4	2	3	3	3	3	3	3	2	2
Difficulties Making Decisions	4	3	4	3	3	2	2	3	3	2
Distressed	3	2	2	4	3	3	3	4	3	2
Enough Company	2	2	3	4	3	3	3	3	3	3
Fed Up	3	3	3	3	2	3	3	3	3	2
Feeling Useful	3	2	3	3	3	2	3	3	2	4
Finances	2	4	3	3	3	3	2	2	2	3
Frustrated	4	2	2	3	3	3	2	2	2	2
Full of Energy	2	1	2	3	4	4	2	3	3	2
Getting in Touch With People	2	3	3	4	2	2	3	3	2	1
Getting Things from Shops	2	3	2	3	3	2	2	3	2	2
Helping Others	3	2	3	2	2	4	3	3	2	3
Irritable	2	3	2	2	3	3	2	2	2	2
Lively	3	3	2	2	3	3	2	3	3	3
Long-Term Memory	3	1	1	3	2	2	2	2	2	3
Look Nice	2	3	3	3	3	4	2	3	2	3
Making Self Understood	3	4	2	3	2	2	3	2	3	2
Memory in General	3	3	3	4	2	2	3	2	3	2
Paying for Things	3	2	1	3	3	3	3	2	2	2
Physical Health	2	3	4	2	3	2	2	4	3	2
Remembering Day	3	4	2	3	2	3	3	3	4	4
Remembering Names	2	3	3	3	3	4	4	3	2	2
Remembering Place	2	3	2	2	1	3	3	2	4	3
Sad	2	2	2	2	2	2	3	2	3	2
Short-Term Memory	2	1	3	2	2	1	2	3	4	2
Things Taking Longer	3	3	2	3	2	2	2	4	3	3
Things to Look Forward to	3	2	2	3	2	2	3	2	2	2
Thoughts Muddled	2	2	2	3	4	2	2	3	3	2
Washing/Bathing	3	2	2	3	2	4	3	3	4	2
Worried/Anxious	3	2	3	3	3	3	2	3	3	2
Total	83	78	77	89	80	83	79	87	83	73

QoL breakdown by item
and resident

Feeding back and discussing data with interest holders

Core team to draft feedback reports, accommodating regional needs (Summer 2025)

Disseminate facility-level reports to participating facilities and region-level reports to region-level decision makers and general public (including caregiver organizations)

Virtual feedback summits (Fall 2025): Presentation of findings, panel discussion, recorded break-out discussions, report back

Data analysis, summary report: interest holders' input on findings (relevance, alignment with their experiences, additional context, implications, possible next steps/improvement strategies, ...)

Final thoughts from Hom and Sam

Questions?



Matthias Hoben (he/him), RN, Dr rer medic
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